

**MEDICAL DECISION-MAKING FOR YOUTH IN FOSTER CARE PLACED IN
CONGREGATE CARE SETTINGS**

by

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Abstract

Every year, hundreds of thousands of children are placed in the foster care system. Of those, tens of thousands are placed in congregate care settings, such as group home and residential treatment facilities. While pediatric medical decision-making is traditionally the responsibility of parents, for youth in foster care placed in congregate care settings, medical decision-making becomes more complex. In current practice, the authority to make medical decisions for these youth is split between biological parents and the child welfare agency. I argue that instead, medical decisions should be made by the youth themselves, provided they meet age and capacity requirements.

There are three primary arguments in favor of allowing youth in foster care in congregate care settings to make their own medical decisions. There is the importance of emerging autonomy, and the role that medical decision-making can play in developing autonomy as well as the importance of respecting the autonomy that is present. There is the importance of control, and returning control to youth who, by nature of being in foster care and particularly in congregate care, have very little control in their lives. Finally, there is the reality that youth in foster care placed in congregate care settings know themselves better than anyone else. After establishing the arguments in favor of the proposal, I will respond to objections, namely the risk of providers manipulating youth, presenting youth with a false choice, and lack of capacity of youth. In weighing the arguments supporting the proposal, the objections, and the response to the objections, it is evident that youth in foster care placed in congregate care settings should be allowed to make their own medical decisions.

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Introduction

When children have been abused or neglected, or their parents or guardians are otherwise unable to meet their needs, the state intervenes to remove these children from their home and place them in out-of-home care, often referred to as foster care. (Children's Bureau, n.d.). Most children in foster care are placed with a relative or foster family in the community. However, some are placed in group homes or residential treatment facilities, referred to as congregate care settings (Children's Bureau, n.d.). In 2019, 10% of children in foster care, a total of over 43,000 children, were placed in congregate care settings (Children's Bureau, 2020).

Congregate care is intended to address specialized needs that cannot be met in a family setting. This includes higher levels of supervision and structure. Mental and behavioral health needs that require more intensive care than can be provided in the community are common reasons for placement into congregate care. Other reasons include physical needs, intellectual or developmental disabilities, and pregnancy or parenting (Children's Bureau, n.d.). When used for mental and behavioral health needs, congregate care is intended to be therapeutic in addition to addressing immediate safety needs through structure and supervision. In theory congregate care should never be used merely as a placement, although in reality that does occur.

When children and youth enter foster care, the child welfare system is responsible for ensuring that their medical needs are met. Yet, the bureaucratic complexities of making medical decisions for children in foster care can threaten the receipt of timely and appropriate care. Legally, as long as their parental rights have not

been terminated, biological parents retain the authority to make medical decisions on behalf of their child. However, obtaining parental consent for every decision is impractical, due to the time-sensitive nature of some medical decisions and the difficulty in contacting biological parents, which is why the child welfare system is typically given joint medical decision-making authority for children in their custody. When it comes to routine care decisions (e.g., immunizations, treatment of common illnesses), the child welfare system can delegate the child's foster parents to make such decisions. For serious decisions (e.g., surgical procedures, use of anesthesia, prescribing psychotropic medications), the biological parents or child welfare agency must provide consent. And for life and death decisions (e.g., experimental treatments, do-not-resuscitate orders), the decision may be left to a judge. This dispersion of decision-making authority is not only confusing for medical providers but can lead to logistical barriers that delay medical care. Locating the biological parents or contacting the child welfare agency takes time, and even when reached they may not respond immediately.

The process of medical decision-making becomes more challenging for youth without foster parents, such as those in congregate care, where even routine care decisions must be made by the child welfare system or biological parents. This can often lead to further delays or disruptions in medical care, feelings of powerlessness for the adolescent who is being treated, and situations where the person making the decision does not know the youth well. With these issues, current practice is insufficient.

In this thesis, I will argue that youth in foster care placed in congregate care settings aged 14 and older should be allowed to make their own routine medical decisions if they meet decisional capacity requirements. Those aged 16 and older

should be allowed to make more serious medical decisions, if they meet decisional capacity requirements. However, decisions that are expected to be life and death should still require the age of 18 as the threshold for decision-making, as they currently do.

First, I will explore why current practice is insufficient. I will provide two contrasting case examples of youth in foster care in congregate care with medical needs. I will then explain my proposal by providing further details on age and capacity requirements and specifying the types of medical decisions to be made, looking to both adult guidelines and mature minor doctrines as frameworks. Then I will present three main arguments for my proposal: 1) the loss of control in congregate care settings, which makes it important for youth to regain control, 2) the importance of supporting youths' emerging autonomy, especially for those in congregate care settings, and 3) decisions should be made by the person who knows the youth best, in this case the youth themselves. I will then highlight and refute likely objections, including the risk of providers taking advantage of youth, the possibility of a false choice, and doubts around the decision-making capacity of youth. Finally, I will return to the case examples and examine how they should be handled under the proposed framework.

Defining the Problem

For the above proposal to have value as a change, there must be insufficiencies in current practice. Medical decision-making as it currently exists for youth in foster care placed in congregate care settings is inadequate. The complex process has many gaps leading to delays, disempowerment, and poor decisions.

In current child welfare practice, medical decision-making is typically shared between biological parents and the child welfare agency. Biological parents whose parental rights have not been terminated retain the right to make medical decisions, although in practice this is typically only invoked for non-routine care. Foster parents act as a surrogate for the child welfare agency to make routine decisions, and judges intervene in more serious decisions or in cases of conflict between the biological parents and the child welfare agency (Seltzer et al., 2020). In practice, this usually amounts to foster parents making the routine decisions. I propose that those youth in foster care placed in congregate care settings aged 14 and older who meet capacity requirements should be allowed to make these decisions for themselves. Currently, biological parents and/or the child welfare agency make more serious decisions, which I propose those youth aged 16 and older who meet capacity requirements should be allowed to make. Finally, currently the courts make the most serious decisions, which in my proposal would still remain under court jurisdiction until the age of 18.

Routine, more serious, and most serious are vague terms that are open to interpretation. For the purposes of this thesis, routine medical decisions include preventive healthcare (e.g. immunizations, routine lab work, well visits) and evaluation and treatment of common illness. More serious decisions include surgery, anesthesia, and psychotropic medication, although psychotropic medication is unique in that youth ages 16 and older may consent to psychotropic medication currently. The most serious decisions are decisions that are reasonably expected to be life-or-death, and experimental treatments. It is impossible to categorize every single medical procedure

and treatment, so clinical judgement is necessary to identify what type of decision is being made.

There are many issues with current practice and the way it applies to youth in foster care placed in congregate care settings. Perhaps most evident is the absence of foster parents. The people who are supposed to be available to make routine decisions do not exist. In their absence, decisions must be made by biological parents and the child welfare agency, which raises its own issues. Biological parents may be difficult to find, especially in time-sensitive situations. Waiting for their consent can lead to delays in care that negatively impact the youth's life, as in the case of C and the pain she experienced waiting for her wisdom teeth to be removed. There are similar issues with the child welfare agency. Child welfare workers may be difficult to reach, or the decisions may need to be raised through the chain of command to a supervisor or administrator, which takes time and causes delays (Seltzer et al., 2020). This is especially true outside of standard business hours. Although child welfare agencies typically have someone on call at all times, that person may not be familiar with the youth and locating someone who is could take time.

In addition to the practical delays, current practice can be disempowering to youth who are already disempowered. Youth in foster care in congregate care settings have lost so much control in their lives, both from being removed from their homes and from their placement in congregate care. Not only do youth not have control in this area of their lives, that control is held by the very people who are responsible for their circumstances, namely their biological parents and the child welfare system. Further, this control that youth are lacking is in a very intimate part of their lives. Decisions about

body and health are some of the most personal decisions a person can make, and not having authority over that can lead to feelings of powerlessness (Sheridan et al., 2015).

Finally, in current practice, the decision made may not be the best one for the specific youth and circumstances. Decisions are being made by people with limited knowledge of and contact with the youth. While some decisions may be able to be made based solely on the science and medicine, many require knowing the youth holistically as a person. For example, while a blood transfusion may be the standard treatment for a particular condition, alternative treatments may be necessary for those with religious objections. Without that knowledge, decisions are being made in the best interest of a prototypical youth, not the youth in question.

Given the practical and psychological consequences of current practice, it is clear that not only is current practice not best practice, it is insufficient and fails to meet the standards that youth deserve. I propose allowing youth to make their own medical decisions, based on capacity and age, as a way of addressing the primary insufficiencies in practice as it exists today. Although it may not be a perfect solution, it gets to the heart of the issue, both logistically and for the youth as emerging adults.

Illustrative Cases

One of the best ways to understand the issues in current practice is to look to individuals and their experiences. Below are two distinct, real-life cases of youth in congregate care settings.

C was a 17-year-old girl with no physical or mental health diagnoses. She entered foster care at age 15 because she was homeless and her parents could not be

located. Her parents continued to be absent and unavailable for input on their daughter's healthcare needs throughout her time in foster care. C was initially placed in a youth shelter. From there she went to a foster family. After over a year with the foster family, there was conflict where the foster family was not meeting her needs, and it was determined that she would leave the foster family. Her leaving the home was not in any way the result of her own actions. No other foster homes were available, so despite not having any diagnosis that would warrant placement in a group home, C was placed in a group home. At the group home, staff at the facility learned that her wisdom teeth had been causing her pain for months, but the foster family never addressed it. After months of considerable pain, it was clear that she needed her wisdom teeth removed promptly.

H was a 16-year-old girl with asthma, pre-diabetes, and inadequately treated depression, anxiety and PTSD. She also self-harmed and had a history of running away without bringing her medications, including her inhalers. She was placed in a group home due to her inadequately treated mental health diagnoses. When she continued to run away, she was placed in a locked residential treatment facility. H often acted impulsively, and did not understand the consequences of her actions, such as leaving her medication behind when she ran away. She often acted in ways that did not align with her long-term desires. H's father was completely absent and unavailable for any consultation about his daughter's complex health needs. Her mother was sporadically involved, but she could go months without contact with H or the child welfare agency. Lacking any parental input, it became more complicated to determine who should have the final determination about her medical treatments. H's doctor was proposing a change to her pre-diabetes medication, and a decision needed to be made whether to

continue with the current medication or switch to the new medication recommended by the doctor.

Proposal

With C and H in mind, I propose allowing youth in foster care in congregate care settings to make their own medical decisions. This would be based on capacity and age requirements, with restrictions in place as a safeguard. Capacity requirements, as well as who determines capacity, will be clearly defined.

Capacity is not a binary that is either present or absent. It comes in degrees. Capacity to make one decision does not equate to capacity to make all decisions. Therefore, I propose an age-based spectrum of decision-making. Youth in foster care placed in congregate care settings ages 14 and older who meet capacity requirements would make decisions for routine care as previously defined. At 16 and older, youth meeting capacity requirements would be able to make more serious decisions. The most serious decisions, such as do not resuscitate orders and refusing life-sustaining therapies, would still require the age of 18.

However, this decision-making authority would not be absolute, just as it is not absolute for parents or guardians. When parents or guardians make decisions, including medical decisions, that are contrary to the best interest of the child, the state and legal systems can intervene (Black, 2006). There is some debate that the best interest standard is not the right threshold, and that state intervention should be based on the harm principle, where states could intervene only if a certain level of harm is likely to occur (Diekema, 2004). Clearly, states have no foolproof way of either assessing the

best interest of the child or determining a level of harm, but there are safeguards in place to protect children from parental harm resulting from improper medical decisions. These include medical neglect statutes that allow for intervention by the child welfare system in cases where medical needs are not being adequately addressed. Similar safeguards would also be possible for youth making their own decisions.

While age requirements are straightforward, capacity requirements are more nuanced. There are two existing frameworks that can provide guidance in this area: adult capacity guidelines and mature minor doctrines. Both of these frameworks look to bioethics and state laws to determine decisional capacity.

In determining decision-making capacity in adults, the CURV mnemonic is used: choose and communicate, understand, reason, and value (Chow et al., 2010). First, the patient must be capable of making a choice and then communicating that choice to providers. They must demonstrate that they have a strong understanding of the choices available, including risks and benefits. They must be able to clearly communicate the choice that they make. They must be able to use reasoning in their choice, and they need to be able to provide the reasoning that led to their choices. Finally, the choice made should align with their preexisting values.

In addition to adult capacity guidelines, mature minor doctrines can offer guidance in determining decisional capacity. Not every state has a mature minor doctrine, and there is variance in those that do. Despite this, common themes can be found. While some states require a judicial opinion of a minor's capacity, many states do not. The states that do not require a judicial opinion allow for medical providers to make determinations of capacity independently (Coleman and Rossoff, 2013).

An example of a current state's mature minor doctrine that is most relevant to this thesis is Tennessee. Tennessee utilizes the rule of sevens, common in tort law, where youth under seven have no capacity, ages seven to fourteen have the presumption of no capacity, but it is rebuttable, and those fourteen and older have the presumption of capacity, but it is rebuttable (Cardwell v. Bechtol, 1987). Additionally, Alaska and Kansas are also relevant, as both allow minors (16 and older in Kansas, any age in Alaska) to make decisions when biological parents are unavailable, which is often the case for youth in congregate care (Coleman and Rossoff, 2013).

With these capacity requirements, it may seem that most youths in congregate care settings would not be capable of meeting the standards to make their own medical decisions. Given the current capacity requirements, youth with intellectual disabilities and those with untreated or inadequately treated mental health conditions would likely be excluded. These are common reasons for youth to be placed in congregate care (Children's Bureau, n.d.). Although such diagnoses are not inherently a basis for exclusion, if the needs associated with a youth's diagnoses are significant enough to require the level of care provided by congregate care facilities, it is likely that youth would also not meet capacity requirements. While an individual with inadequately treated mental health conditions may be able to meet the CURV standard, if their needs are so significant that they need congregate care to manage daily life that becomes less likely.

However, over 40% of youth in congregate care do not have a physical, intellectual, mental, or behavioral diagnosis that would indicate such a placement (Annie E. Casey Foundation, 2015). With the previously mentioned 43,000+ youth in

congregate care settings, this means there are over 17,000 youth that have the potential to meet capacity requirements.

Argument One: Returning Control to Youth

With both the problem and proposal defined, the next step is to explain how the proposal addresses the problem. There are three primary arguments to support this connection. The first argument focuses on returning control to youth. For youth in foster care in congregate care settings, control is often lost. Medical decision-making is a way to return control to the youths in one domain of their lives.

The removal from their home, placement into congregate care, and the structure of congregate care are all beyond their control in ways above and beyond the limited control that a typical youth has. Having taken so much control away from these youths, we owe it to them to try and return some control in the form of medical decision-making.

Group homes and residential treatment centers are described as “highly structured environment[s]” (Children’s Bureau, n.d.). But what does “highly structured” mean? Nearly 40% of youth in congregate care settings are locked in their rooms at some point. That jumps to 70% for public facilities run by local governments. A quarter use mechanical restraints, such as handcuffs and bed straps (Hockenberry et al., 2011). These physical restrictions are just one way in which youth lack control in congregate care.

Every facility is different, and many do not make their rules publicly available. However, Fremont County Group Homes provides their resident handbook online. Rules include limited phone calls, no over-the-counter medications, no money, no loose

pants, no earrings, no snacks without permission, no going downstairs, and an 8:00PM bedtime (Fremont County Group Homes Inc., n.d.). This is representative of many congregate care settings, including H's experience. H was allowed to work but not allowed to keep any of the money she earned. She could not have a phone, spent hours at a time confined to her room, and could not take so much as a Tylenol without approval from her worker. Although stories from H and the Fremont County Group Homes handbook are anecdotal, they provide insight into the realities of living in a congregate care setting.

Youth in foster care in congregate care settings clearly do not have control over their lives, but why do they need it? Control is a form of self-determination. Control in one's life is about having the power and authority to make decisions for oneself. In some views, self-determination is a dimension of well-being, and as such is inherently valuable (Powers and Faden, 2019). This means that youth cannot attain wellbeing completely without some degree of self-determination.

It is clear that control is important and that youth in foster care in congregate care settings lack control over their own lives. But why focus on medical decision-making as a way to return control? First, it is intimate. One's body and health are incredibly personal. Medical decision-making is not just control in daily life; it is control of something that is so unique to the youth that allowing others to make such decisions feels invasive.

Second, it is impactful. Health greatly influences a person's life and overall wellbeing. Having control over health may not directly improve one's health, but is necessary to have full control over one's life. The gravity of the decisions being made

impacts the youth's feelings of control. Making medical decisions gives a greater sense of control and empowerment to youth than more minor decisions would.

Third, it does not impact others. The more obvious solution to the restrictive nature of congregate care is to give youth more control over their day-to-day lives. However, this is often impossible due to the number of youths living in any given congregate care setting and their conflicting wants and needs. Medical decision-making is something that each youth can do independently, without impacting those around them.

Finally, it is achievable. When maltreatment means that living with biological family is unsafe and limited resources means congregate care is the only living option available, control over where to live is impossible. Youth cannot make their families safer. They cannot make more foster families available with skills needed to meet complex needs. When there are so many youths in any congregate care setting with unique needs that must be met, control over day-to-day decisions is impossible. There is simply not enough staff to accommodate youth all eating at different times, or all sleeping on different sleep schedules. As providing youth with control in these simpler day to day decisions is not feasible in the group setting, we must turn to more creative ways to return control to youth in foster care placed in congregate care settings. Medical decision-making is one such way.

Argument Two: Emerging Autonomy

Control is closely connected to autonomy. It is difficult to have control without autonomy. While control looks at an individual decision and the power over it, autonomy looks at the individual and their right to be making decisions for themselves.

Emerging autonomy is part of the process that develops completely non-autonomous, dependent infants into fully autonomous, independent adults. Emerging autonomy can begin in early childhood, with decisions such as which arm to receive a shot in. Adolescence is a time of significant development of autonomy as adulthood nears. Emerging autonomy is important in general, but also more specifically in the context of healthcare. The World Health Organization finds that supporting emerging autonomy positively impacts healthcare utilization of adolescents (WHO, 2017).

Traditional pediatric shared decision-making supports developing autonomy and recognizes its importance. The American Medical Association's Code of Medical Ethics states that parents ought to support children in developing the ability to make decisions for themselves (AMA, 2016). The emerging autonomy of all youth should be respected, recognizing that they do have some level of decision-making capacity (Friebert, 2010). Friebert (2010), argues that emerging autonomy should be respected up to and including life-and-death decisions.

Emerging autonomy is important for all youth, but it is especially important for those who are likely to be aging out of foster care and without support at 18. Young adults often rely on familial support financially, emotionally, and physically, well past their 18th birthday (Rosenberg and Abbott, 2019). Those aging out of foster care from

congregate care settings do not have that same support. They will not have the same familial support and guidance in decision-making as their peers outside of foster care, or even those in foster care not in congregate care settings.

Some may argue that with extended foster care lasting until age 21, the development of autonomy by 18 is unnecessary. However, the option of foster care until 21 does not mean that all youth will remain in foster care until 21. As of 2019, only 26 states had extended foster care. Those that did usually have some form of education and/or work requirements, and after living in the restrictive environment of congregate care, these young adults are often likely to reject anything they perceive as putting demands upon them. (United States Government Accountability Office, 2019). For youth living in the 24 states without extended foster care, youth who fail to meet education or work requirements, and those who choose to leave care at 18, there is still great importance in making sure that youth who live in congregate care, more than youth placed with foster families or relatives, receive all the support and opportunities necessary to achieve sufficiently developed autonomy by 18.

The process of aging out of congregate care is made significantly more abrupt by its restrictive nature (Domanico, 2016). As discussed previously, every aspect of life in congregate care is structured, with little opportunity for youth to exercise their developing autonomy. Regardless of whether this abrupt transition to adulthood is the root cause, youth who age out of congregate care settings have far worse outcomes than their peers who age out of other foster care settings. They face increased homelessness, more poverty, and more frequent physical and mental health diagnoses, as well as poor educational attainment and lower employment rates (Domanico, 2016).

Emerging autonomy is even more important for youth in foster care placed in congregate care settings than for other youth because their lives are so strictly regimented. It is far more difficult for these youth to express any sort of autonomy. Additionally, youth in foster care often struggle with attachment and emotional regulation (Barnett, 2020), which are fundamental to the development of autonomy. Autonomy is a skill that must be practiced, and even small opportunities like spending time with friends and planning family activities are often not available to youth in foster care, much less those placed in a congregate care setting. Without the foundational attachment and emotional regulation, combined with limited opportunities to practice autonomy, youth in foster care in congregate care settings are doubly disadvantaged in the development of autonomy.

Thus, youth in foster care placed in congregate care settings face two main barriers to becoming fully autonomous adults. First, they have far fewer opportunities to exercise emerging autonomy, which leads to an inability to develop the skills necessary to become fully autonomous. Second, upon aging out they are expected to be fully autonomous adults overnight. This is an unrealistic expectation for any youth, with or without family to support them. As such, there must be some sort of gradual introduction into autonomous decision-making within the congregate care setting.

Ideally, this gradual introduction would come by having more supports for youth, both while in foster care and upon aging out. However, we live in a non-ideal world, and while changes can and should be made to the foster care system to minimize use of congregate care and increase multiple types of supports both in congregate care and beyond, there are youth who need this action now. If we wait for the foster care system

to adequately address the needs of the youth it serves, thousands will go without the support they need in the meantime.

In the absence of an ideal solution, I propose a spectrum approach to decision-making for youth in foster care placed in congregate care settings. This type of decision-making approach allows youth to make decisions that are increasingly serious as they age, so that they have an opportunity to exercise their autonomy in lower stakes situations and gradually work up to more serious decisions. My proposal also provides a safety net for the youth, where the state can intervene if the youth is at risk of serious harm. These guidelines allow for a safe, controlled environment for youth in foster care placed in congregate care settings to successfully exercise their developing autonomy.

Argument Three: Youth Are Experts on Themselves

In addition to the agency and developmental considerations of emerging control and autonomy, there are practical reasons for youth in foster care in congregate care settings to make their own medical decisions. Decisions ought to be made by the people who know the youth best. For youth in foster care in congregate care settings, this is the youth themselves.

The belief that decisions should be made by the people who know children best is part of why we, as a society, allow parents to make medical decisions for their children (American Medical Association, n.d.). For youth in foster care placed in congregate care settings, a determination of who knows the youth best is complex. Biological parents, social workers, group home staff, and judges all have either limited or short-term contact, and there are no foster parents. By process of elimination, there

is typically no one left but the youth who knows them well enough to be making medical decisions.

If decisions are going to be made in a youth's best interest, it seems clear that the person making the decisions needs to know the youth well in order to make the decision appropriately. It is counterintuitive that the more serious a decision is, the more removed the decision-maker is (Seltzer et al., 2020). The relationships between the youth and decision-makers are typically inadequate to truly know the youth.

Every state is required to offer visitation to biological parents; however, there is no uniform standard for visitation that is applied in all fifty states. As such, the frequency and circumstances of the visits vary greatly from state to state and are often subject to interpretation of the child welfare workers and the judges not just in every state but even every county. Texas requires less frequent visitation for adolescents than younger children, and their legislation simply states that biological parental visitations should be regular (Texas Department of Family and Protective Services, 2015). Washington also requires less frequent visitation for adolescents than younger children, requiring only 30-60 minutes once a week (Partners for Our Children, 2014). Alaska requires "reasonable" visitation, where reasonable is determined by the child welfare agency (FindLaw, n.d.). Such limited contact, especially for youth who have been living out of the home for an extended period of time, is insufficient to truly know the child best.

Even if an hour visitation each week were sufficient for a biological parent to know the child best, it is not guaranteed that this hour visitation occurs. Although practice guidelines require that the child welfare agency offer visitation, it may waive

that time if it is determined to be counter to the child's best interest. Again, this determination is vague and typically made by the child welfare agency. Further, even if visitation is offered as mandated, that does not mean the visitations will occur. Parents may be unable or unwilling to visit their child, and what is supposed to be weekly contact often becomes sporadic or even non-existent.

In the absence of biological parents, child welfare agencies are left to make all medical decisions for the children under their care. Despite this authority, the agency and its staff often do not know the youth well. If the decision is being made by a supervisor or administrator within the agency, it is likely that they have never met the youth. Even case workers who are supposed to be the primary contact for youth are only required to see them monthly (Child and Family Services Improvement Act, 2006). This monthly contact is often not with the same case worker for long, as turnover rates are estimated between 20 and 40 percent annually (Annie E. Casey Foundation, 2017). Most case workers are not interacting with youth frequently enough or long enough to be the person who knows the youth best. Youth are aware of this constant change, and they recognize and identify case worker turnover as a challenge in their lives (Strolin-Goltzman et al., 2010).

Judges are often expected to make the most serious medical decisions for youth in foster care placed in congregate care settings. While their judicial objectivity is valuable, it is important to remember just how limited their contact with the particular youth often is. Depending on the judge and the circumstances, contact typically ranges from once every six months to nonexistent (Seltzer et al., 2020). This highly limited

contact is not enough to truly know all the factors that go into determining the youth's best interest.

Not only do youth in foster care placed in congregate care settings know themselves best, but they are the only person who is always there. With a revolving door of staff taking youth to appointments, the current decision-maker is likely not the person at the appointment with the youth. The decision-maker must be identified, located, and then they must make their decision and communicate it to the providers, which is often a drawn-out process. Having youth make their own decisions not only means that it is the person who knows best, but also the person who can give the most timely response making the decisions.

For youth in foster care placed in congregate care settings, there are no foster parents. Biological parents, case workers, and judges all spend limited time with youth. There is no one but the youth who know themselves best. Much like with emerging autonomy, it is important to recognize that this is not ideal. There should be someone in youths' lives that know them well enough to make decisions for them, and the child welfare system should work to build those relationships. However, youth have medical decisions that need to be made now and cannot wait until such relationships have been built. In the absence of such relationships, youth in congregate care settings should be recognized as the person who knows themselves best, and their role should be respected by allowing them to make their own medical decisions, provided they meet certain age and capacity requirements.

Objections and Rebuttals

Objections could be raised to this proposal. A first objection is that providers may use their authority and power to either manipulate youth into making certain decisions or to determine capacity based on the youth's compliance. A second objection is that decisions will only be allowed to be made if they are aligned with what traditional decision-makers approve of, and thus youth are not truly being given decision-making power. A third objection questions how capable any youth is to make such serious decisions. These potential objections, while having some merit, are ultimately insufficient to overcome the arguments in favor of the proposal.

All children are vulnerable. Those in foster care are even more vulnerable, and those placed in congregate care settings are more vulnerable still. The absence of loving and stable adults increases youths' vulnerability, as does the emotional and mental impact of the trauma they have experienced by nature of being removed from their home and placed into congregate care. With such vulnerability, there is the risk of medical providers manipulating youth into making decisions that providers think is best and determining their capacity based on whether or not the youth agrees with the provider. Providers could find youth have capacity when they do not simply because the youth agrees with the doctor. Conversely, providers could claim the youth does not have capacity simply because the youth questions the provider. The power imbalance between providers and youth is cause for concern.

In response to this objection, the only solution is trust. We trust medical providers with our lives every day. That trust has to extend to trust that they will not take

advantage of youth. This may seem like a weak response to a very valid concern, but trust is already a critical component of every provider-patient relationship. If we cannot trust a provider to not take advantage of a vulnerable youth, we should not be trusting them to provide medical care at all.

Beyond trust, this power imbalance is not unique to youth in foster care in congregate care settings, although it is amplified in these circumstances. Decision-making for children in foster care is often a matter of deference to physician opinion, even when adults are the ones making the decisions (Seltzer et al., 2020). This deference to medical providers is also present for parents and children not involved in the foster care system (Brinchmann et al., 2002). Providers are always in a position to take advantage of children and families. If there is a risk of being taken advantage of regardless of who is making the decision, the reasons for allowing youth in foster care placed in congregate care settings to make their own medical decisions remain.

Another issue with this proposal is what we might call the false choice objection, where giving choice to youth is disingenuous because it only exists as long as it aligns with decisions that would be made regardless of the youth's involvement. Are we only allowing youth to make decisions that we agree with? Is it truly their decision if the state can intervene at any moment? There is some truth to the claim that we are giving youth a false choice. If they make a choice that the state feels is wrong, whether the best interest standard or harm principle is used, they lose the right to make that choice. This is especially concerning because youth are aware when they are being given a false choice and express justified frustration (Coyne et al., 2014).

However, to some extent, all choice in pediatric decision-making is a false choice. The state can intervene whenever parents or guardians make a decision (Black, 2006). This only occurs if the decision reaches a level of severity where it becomes necessary. If there will be limitations of decision-making regardless of who is making the decision, then such limitations are not a sufficient reason to not allow youth in foster care in congregate care settings to make their own medical decisions.

Further, the false choice objection does not invalidate the arguments in favor of the proposal. Emerging autonomy is still exercised in a safe and controlled manner. Youth still have control up to a certain threshold, and youth still know themselves best. Without invalidating the premises or logic of the argument, the conclusion still stands.

Finally, there is a more fundamental objection, which is whether any youth can truly have capacity to make the decisions proposed in this thesis. Further, these are not just any youth, but youth who have experienced significant trauma. Childhood maltreatment, which is the reason most youth are in foster care, negatively impacts executive functioning, including planning, problem-solving, and other skills relevant to medical decision-making (O'Rourke et al., 2020). This proposal would allow youth we know are at risk for decreased executive functioning the opportunity to make their own medical decisions.

However, just because a population has an increased risk of something does not mean that every such individual will be affected. Heightened risk does not guarantee a particular outcome. Even with a heightened risk of decreased capacity compared to youth not involved in the child welfare system, there are still many youths who would not have decreased capacity. Additionally, this is the purpose of the capacity requirements.

There are guidelines in place to protect against this concern. Finally, the age of 18 is arbitrary. Capacity does not change overnight, and someone who has capacity at 18 likely had capacity at 17 and a half. Those youth who do not have capacity at 17 are not likely to gain it automatically on their 18th birthday. Capacity should be built through practice prior to 18, which medical decision-making facilitates. If we accept the capacity of an 18-year-old to make decisions, which legally we do, we must also accept the possibility of decisional capacity in those under 18.

Conclusion

Let us now return to C and H. In reality, neither was allowed to make their own medical decisions, although both did assent to the decisions that were made about their care. Would this proposal for allowing youth in foster care placed in congregate care settings to make their own medical decisions change their outcomes?

C was 17, so she fell in the age bracket to make more serious decisions including surgery. She had no ongoing mental or physical health conditions, and nothing to indicate that she would not meet capacity requirements. Based on this proposal, C should be allowed to make the decision regarding her wisdom teeth removal. This would have prevented delays in care that developed due to the current decision-making process, delays which led to the need to remove a more painful impacted tooth rather than a planned removal.

H was 16, so age-wise she was in the category to make both routine and more serious decisions. However, she had several inadequately treated mental health diagnoses that impacted her capacity to make decisions, as evidenced in part by her

poor medication compliance. Although the decision to change her prediabetes medication would be considered routine, she does not meet capacity guidelines and as such would not be allowed to make this decision. While there are safeguards in place to protect against harmful decisions, it is disingenuous to allow youths who do not meet capacity guidelines to make decisions on the basis that these decisions could be overruled.

C and H are ideal cases to examine for this framework because they are so different. C shows the importance of allowing youth to make their own decisions. H shows that this authority needs boundaries and will not be applicable to all youth.

Youth in foster care in congregate care settings face many challenges unique to their circumstances. As a result, their needs are different. They have a heightened need for emerging autonomy and control, and a need to have their role as the person who knows themselves best respected. One way to partially accomplish this is by allowing them to make their own medical decisions in a safe and controlled manner, with age and capacity requirements as well as the opportunity for state intervention when the risk of harm is too great.

This proposal is not without flaws. Concerns of providers manipulating youth, false choices, and questions of capacity are all valid issues. However, they are issues that are either addressable or present regardless of who is making the decision and as such do not justify rejecting the proposal. With so much to gain and protections in place against the risks, youth in foster care in congregate care settings should be allowed to make their own medical decisions.

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